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Supporting Carers of People with Dementia: What is Effective?

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Declarations of Interest: None

Abstract

Carer stress is well documented, especially in those caring for individuals with dementia. A recommendation of all national dementia strategies is to provide excellent support and information to carers of people with dementia. NICE guidance suggests that a range of tailored interventions including psychological input, psychoeducation and training courses should be offered to reduce caregiver burden and stress, although good quality outcome based evidence is lacking. On the basis of a narrative review of the literature, we describe current individual and multi component carer support packages available and discuss their evidence base, reflecting on outcomes for carers. The best evidence for effectiveness is with multicomponent interventions.

Introduction

The impact of caring for a person with dementia is often described as burdensome (Acton and Kang, 2001) and caring for someone with dementia has also been shown to impact on physical health (Pinquart and Sorensen, 2003, Zhu et. al. 2015) as well as anxiety levels (Cooper et al, 2007) In addition to providing care for people with dementia, health and social care services provide support for carers of people with dementia to improve outcomes for both, and to reduce carer burden. Interventions to aid carers of people with dementia include general carer support, education, formal approaches to care and respite as well as multi component interventions (a combination of different types of interventions).But availability of these interventions varies

nationally, and evidence for their efficacy is at best mixed with considerable heterogeneity in results.

Reviewing the effectiveness of carer interventions is challenging - mixed results from heterogeneous studies challenge the generalisability of results and make it difficult to make appropriate evidence based decisions regarding appropriate and timely support for carers of people with dementia. Furthermore, studies into caregiver interventions are fraught with methodological difficulties, including poor quality (Acton and Kang, 2001), lack of conceptual clarity of outcome measures (e.g. 'burden', which has subjective and objective measures), overlap between intervention types, poor definition of interventions, and small sample sizes which often do not include males or ethnic minorities. The purpose of this review is to provide an update of evidence base for interventions which are principally aimed at carers of patients with dementia. It is important to recognise though that as pointed out by Gitlin and colleagues (2015) most studies are carried out separately from the care system, and may not be reflected in real world practice.

Methodology

We reviewed completed studies of all interventions principally aimed at carers. We searched Medline, CINAHL, PsycInfo, Cochrane, Social care online and ASSIA. The search terms included the key words carer, caregiver and dementia. Studies were only included if they met the required criteria (*Figure 1*). Quality was assessed using 5 criteria - Studies which scored <3 were not included. Interventions were categorized, in keeping with similar previous reviews (e.g. Acton & Kang 2001, Cooper et al 2012), into 8 discrete groups: Counselling & Support, education, Psychology, Occupational Therapy, Formal Approaches to Care, Telecare, Multicomponent or Other.

ASSIA SEARCH:

including keywords: **dement** OR (wernicke encephalopathy) OR (Creutzfeldt Jacob Disease) OR CJD OR (Vasc* dement*) OR (lew* bod*) OR (lewy body) OR **alzhem*** OR **alzheimer's** OR **alzheimer's** OR **alzheimers** OR **ab(Dementia)** OR **dementia** AND (caregiver OR **caregiv*** OR **carer**) AND yr(2006-2013)

n= 132

CINAHL SEARCH:

Search including keywords: **Dementia** OR **Dementia**, **Vascular** OR **Delirium**, **Dementia**, **Amnestic**, **Cognitive Disorders** OR **Dementia**, **Multi-Infarct** OR **MH Lewy Body Disease** OR **Dementia**, **Presenile** OR **Dementia**, **Senile** AND **Caregiver Burden** OR **Caregivers** OR **Caregiver Support**

n= 215

MEDLINE SEARCH:

Search including keywords: **Delirium**, **Dementia**, **Amnestic**, **Cognitive Disorders** AND **caregiv*** or **carer**

n=454



Studies reviewed for inclusion using following criteria:

- A study of population of adult caregivers of patients with dementia, Community based, Single study design (i.e. not a review or meta analysis), Completed study (i.e. not a study protocol), Reported outcomes principally target caregiver and patient with dementia, English only, Published 2006-2016

N = 253



Study quality assessed using following criteria

- Randomisation
- Similarity between intervention and control grouped
- Minimum 10 participants in each group
- Attrition rate
- Use of well validated outcome measures

Studies which scored <3 excluded



56 Studies

Figure 1: Methodology

Results

Counselling & Support

Counselling and support groups are informal, mutually supportive and often run by the third sector.

Carers anecdotally report strong benefits from peer support of others 'in the same boat' as them. Often counselling is provided in settings out with health and social care settings, which may increase accessibility.

Counselling and support groups have shown to benefit carers in a number of ways including reducing burden (Wang, 2011; Chien, 2008), depressive symptoms (Mittleman, 2008; Ulstein, 2007), and improving quality of life. There is also evidence to suggest improvements in carer self-rated health (Mittlemann, 2007) and greater overall satisfaction with care giving role (Mittlemann, 2007). Comparative studies between existing support groups in different settings (i.e. day hospital and 3rd sector groups) suggest no benefit of one over the other (Bartfay, 2013). More structured counselling interventions, delivered over a specified period of time (Joling, 2012) while anecdotally reduce burden in carers have not significantly demonstrated benefit. Perhaps this suggests a more flexible, less prescriptive approach is better.

Educational Interventions

Educational interventions are any interventions which primarily aim to impart knowledge or skills to aid carers in their caregiving role. Dementia education is a priority in the U.K. and most post diagnostic follow up includes a component of psychoeducation. However, evidence is mixed (table 1) and larger studies (Kurtz, 2010 and De Rotor, 2011) failed to demonstrate any benefit in their measured outcomes.

Study	Number	Measure	Intervention	Outcome
Kurz, 2010	156/136	Depression QOL Time spent Caregiving	7 bi-weekly group sessions	No significant differences
De Rotrou, 2011	79/78	Depression	12 weekly group sessions	No significant difference
Ducharme, 2011	62/49	Confidence Self efficacy Coping Ability	7 weekly group sessions	Greater confidence, self efficacy and coping ability
Chien, 2008	44/44	QOL Burden Level of Social support	Workshop 12 sessions over 6 months	Reduced burden and increased QOL
Dias, 2008	41/40	Overall mental health Burden Distress due to problem behaviours	1 visit per fortnight for 6 months minimum	General mental health improved No change in burden
Kurz, 2007	30/22	Competance Mastery	12 hour training (6 biweekly) Group based	Both increased compared to waiting list control

Table 2: Evidence base for psychoeducation

While psychoeducation may not reduce depressive symptoms, other benefits have been demonstrated in smaller studies including increased confidence in caring (Ducharme, 2011), reduced burden (Chien, 2008), increased competence (Kurz, 2007) and an improvement in mental health (Dias, 2008).

The current 'one size fits all' approach to education groups needs to change - they should be culturally sensitive, and may require to be gender specific. Many published trials have failed to reflect this. Male carers may benefit from a more problem solving based approach, for example.

Psychology

NICE guidance recommends that carers who experience psychological distress as a result of caring should be offered psychological therapy by a specialist practitioner. There is also a role for psychology

in managing problem behaviours, and minimising caregiver distress as a result of these Group based CBT has demonstrated positive results (Losada, 2011) in modifying dysfunctional thoughts and a small but significant benefit in reducing depression. Time is of the essence for many carers – while longer intensive interventions work, many carers may not be able to be able to make a lengthy time commitment due to their ever changing role. Shorter CBT sessions (Marques-Gonzales, 2007) and 2 week intensive CBT interventions (Gitlin, 2010) have also demonstrated benefit on anxiety and depressive symptoms, as has a manual based coping strategy (Livingston et al 2013, Livingston et al 2014)

Formal Approaches to Care

This includes appropriate care management, care programming and use of specialist nurses to deliver care. Formal care management involves 1 clearly identified member of health or social care staff who smoothly coordinates care throughout the patient and carer's journey. Early assessment and identification of problems can trigger appropriate care pathways, often guided by a pro forma consulted by the care manager in collaboration with the carer. The proposed benefits include improved communication between health and social care services, screening for mental health problems and early access to treatment, well-coordinated planned support, timely identification of potential crises, and more organised collaborative care (Lam, 2010). Continuity of staff is key, but in reality very difficult to

achieve (Spiijker, 2011). Additionally, this approach may be too prescriptive for most carers - consequently most studies do not show statistically demonstrable benefits.

To encourage more collaborative care between caregivers and health professionals, Simpson (2006) developed caregiver held care records, with sections for completion by carers, families and health professionals. Use of the record was associated with reduced carer strain, but did not improve carer knowledge of dementia overall nor did it improve health outcomes for carers. This study was however completed before the introduction of widespread cholinesterase inhibitors in the U.K, when patients with dementia were often referred late in their diagnosis and carers may have been under significant strain for a prolonged period. The authors postulate that its use may be of greater benefit to patients and carers in the earlier stages of diagnosis.

An exploratory analysis of data (Connor 2008) examined the significance of a number of variables in a nurse led care management programme. While use of a care manager to explore care options in general was not associated with an improvement in caregiver mastery, specific approaches, such as assessment of the home environment, was.

With regard to patient outcomes, Fortinsky (2009) looked at the impact of development of a targeted, carer held care plan, counselling and collaboration with the carers' GP. Institutionalisation rates (the rate of admission to hospital or a care home), in controls were twice as high as those actively managed: the difference was small but approached significance. Carers who were more satisfied with the intervention showed the greatest improvement in self efficacy, but there were no significant differences specifically on burden or depression, perhaps as the small sample size meant that the study was insufficiently powered to identify small but significant change.

Telecare

Distance based interventions, using telephones and technology, have become increasingly used in recent years. Use of technology in providing carers support may be more convenient for carers, save money both for carers and the provider, and save time in eliminating travel and the need for extra support of the person with dementia during the intervention period. A summary of the evidence is given in table 2.

Author	N intervention/ N control	Intervention	Outcome Measured	Results
Winter, 2007	58/45	Telephone Support Group	Burden Depression Personal gains	No Difference
Van Mierlo, 2011	46/8	Telephone Coaching	Competence Mental Health	Increased Competence Improved mental Health
Gallagher-Thomson, 2010	40/36	Skills Training DVD	Positive affect Depression Stress	Positive affect significantly increased Decreased stress
Tremont, 2008	32/28	Telephone	Depression Burden Reaction to problem behaviour	Lower Perceived Burden Less severe reaction to problem behaviours
Finkel, 2007	23/23	Computer Based	Depression Burden Health Behaviours Social support	No significant effects
Gant, 2007	17/15	Video/ workbook/ telephone	Self-efficacy Positive and negative emotions of caring Upset relating to target complaints	Both interventions improved measured outcomes but video condition not superior
Tremont 2015	133/107	Family intervention telephone support compared with simple telephone support	Depression Burden Reaction to behaviour problems	Improvement in depression ratings and in reaction to behaviour problems

Table 2: Distance based support

The most studied distance based interventions are telephone based, likely due to the fact they are readily available, cheap and do not require training to use. Results into the benefits of telephone interventions are promising, although some studies are of suboptimal quality and involve small numbers. Tremont et

al (2008) showed that a telephone based intervention providing psychoeducation, emotional support and direction of carers to appropriate services was significantly beneficial in reducing caregiver burden and reactions to problem behaviours, identified as a main contributor to caregiver stress. Furthermore, fewer depressive symptoms were reported in those randomised to the telephone intervention compared to controls, although this did not reach statistical significance although this may in part have reflected that those recruited to this study had lower baseline depression scores to comparative studies. A more recent study by the same group demonstrated that a more refined family based telephone intervention reduced depression and reactions to behaviour problems compared to more conventional telephone support (Tremont et al, 2015). In contrast, use of telephone coaching intervention (van Meirlo, Meiland and Droes, 2012) was shown to have a significant large effect (0.96) on mental health complaints (measured using the General Health Questionnaire) and effects were greater when combined with day care compared with day care alone.

With regards to specifically targeting depressive symptoms, an RCT (Gleuckauf et al 2012) showed superiority of telephone based CBT over face to face treatment, although the sample size was particularly small (n=7) and involved African American caregivers only. Groupbased telephone support may also be effective (Winter and Gitlin 2006) Using conference calling technology small groups 'met' weekly to share coping strategies, including cognitive reframing and practical approaches to organising care routines and providing each other with social support. Although there was no difference in overall depression scores at 6 months, older carers appeared to benefit more from the intervention, perhaps, as the authors suggest, because of greater baseline levels of social isolation (there was no significant differences in baseline depression scores). However, older carers also participated in significantly fewer sessions than younger, and as with any 'high tech' intervention which involves some period of learning to use at the start there are concerns that lack of participation may be attributed due to difficulties in using the technology by the older group.

Multimedia (DVD) training programmes have also received some interest. (Liddle, Smith-Conway, et al, (2012) and Gallagher-Thomson et al, 2010). One DVD intervention (Gallagher- Thomson et al, 2010) used role play and narration to illustrate managing problem behaviours, and provided relevant education and strategies for preparing for placement and was compared to a control 'information only' DVD. While both groups showed a decrease in depressive symptoms measured using the CES-D, the difference between groups was not shown to be statistically significant although those in the intervention groups did score significantly higher on the positive affect subscale than controls. Stress related to problem behaviours was also significantly reduced in those provided with the intervention DVD. These findings were not replicated in a more recent study (Liddle et al 2012) which used a brief training intervention focussing on memory and communication between caregivers and the person with dementia – while a greater proportion of carers who received the intervention reported improved perceptions related to their caregiving role (46% vs 13% of controls), this was not significant. Nor was there a significant impact on burden.

A preliminary RCT (Gant et al, 2007) comparing telephone based psychoeducation to combined telephone and video support in male caregivers (n=15,17 respectively) showed benefit in both groups in increasingly positive affect, decreasing negative affect and improving general health (measured by total number of subjective complaints reported), although no superiority of the combined intervention was demonstrated.

Given that many homes now have computer and internet access the use of this to deliver carer support seems promising. Finkel et al (2007) developed a support intervention using a combination of screen phones and computer access to a website to deliver individual education sessions and group based support for 6 months. Similar to other technology based interventions, they did not observe a significant benefit when compared to an information only control although in stratifying the results it did appear that those who were most depressed significantly benefited the most, suggesting that timely delivery of this type of intervention should be considered. However a systematic review (Boots et al, 2013) concluded that internet interventions were not supported by high quality research evidence, and called for further research.

Multicomponent

Multicomponent interventions consist of 2 or more different types of intervention. This may include components of support, counselling, education, respite care and psychology.

There is a moderate positive evidence base for multicomponent interventions (table 3) although there is still debate regarding which components and in which combination are most effective. Trials in this area are often larger, perhaps because recruitment is easier as the intervention is more representative of day-to-day practice.

Reference	Study Type	Intervention	Outcomes	Outcome Measure	Length of Study	Results
Drees (2006)	Pre/ post evaluation	Education meetings Discussion groups Social Activities	Subjective burden Carer Competence	GHQ-28 Modified version of sense of competence scale	6 months	Small effect size on subjective burden

Belle (2006)	RCT	<p>didactic instruction role playing problem solving skills training, stress management techniques, telephone support groups to provide education</p> <p>develop skills to manage troublesome behaviours</p> <p>social support</p>	<p>Carer burden</p> <p>Depression</p> <p>Social Support</p> <p>Self-care</p>	<p>Zarit Burden</p> <p>Interview</p> <p>CES-D</p> <p>10 item questions assessing 3 domains of support(received support, satisfaction with support, negative interactions with support</p> <p>11 questions about CG diligence in looking after self</p>	7 months	<p>3 ethnic groups were studied – Latinos showed less burden, reduced rates of depression, greater social support and self-care</p> <p>Caucasian patients benefitted only for increased support</p> <p>No benefit in the measured domains was demonstrated in Black/ African American participants</p>
Onor (2007)	RCT	<p>Reality orientation or reminiscence for patients with dementia</p> <p>Psychoeducation</p>	<p>Anxiety</p> <p>Depression</p> <p>Carer Burden</p>	<p>Brief symptom inventory (including anxiety and depression subscales)</p> <p>Caregiver burden</p>	4	<p>Reduced anxiety and depression</p> <p>No effect on burden</p>

Holland (2009)	RCT (post study analysis)	REACH programme	Symptoms of normal and Complicated grief	<p>The Inventory of Complicated Grief</p> <p>Texas Revised Inventory of Grief</p>	18	Lower in carers who had received intervention
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Lewis (2009)	Pre/ post study analysis	Stress busting programme: Psychoeducation Support	Perceived stress Depression Subjective CG burden Anxiety	Perceived stress Scale Centre for Epidemiologic Depression Scale (CES-D) Short form 36 health survey Symptom	2	Decreased perceived stress Decreased depression Reduced subjective CG burden
Elonimi-Sulkava (2009)	RCT	Specialist nurse support provided individually tailored interventions Geriatrician assessment and treatment	Self-rated health Sleep quality Physical health Emotional health		24	Improvement in all domains
Gitlin (2010)	RCT	Combined nursing and occupational therapy treatment focussing on problem behaviours	Carer upset Reducing negative communications	Perceived Change Index	24 weeks	Improvement in all domains
Gallagher-Thompson (2008)	Pre/ post study evaluation	Coping with Caregiving Programme: CBT Psychoeducation	Depression General stress Stress at problem behaviours	CES-D 10 item Perceived Stress Scale RMBPC-Conditional Bother subscale		Improvement in all domains Comparison of Hispanic/Latino and non-Hispanic carer groups demonstrated no significant difference between

Villareal-Reyna (2012)	Quasi experimental repeated measures	CBT based mood management CBT + use of humour	Anxiety	Finding significance through care: Attitudes towards Care Scale Inventory of State Anxiety	8 weeks	Reduction in anxiety, greater effect if laughter intervention used
Tremont (2008)	RCT	Emotional support Directing carers to resources Encouragement to attend to own needs	Perceived burden Stress related to BPSD Depression	Zarit Burden Interview RMPBC CES-D	12	Perceived burden and stress significantly reduced No change in depressive symptoms
Chien (2011)	RCT	Key worker allocation Psychoeducation	Burden Quality of Life	Family Care Burden Inventory (FCBI - Chinese) WHO WOL-Bref (Chinese) validity 0.71-0.80	18	Improvement in both
Gitlin, 2010	Prospective	Targeted needs	Well being	Distress measured on a 0-10 Likert scale	24 weeks	Small improvement
	RCT	assessment Education		Zarit Burden Inventory CES-D Perceived change index Task Management		
Nichols(2011)	Pre/post intervention evaluation	Home support Telephone support	Burden Depression	Zarit Burden Interview Patient Health	6	Improvement in All domains
Meeuwssen (2012)	RCT	post diagnostic support Groups telephone GP lead	Perceived burden impact of depression on daily lives	sense of competence Medical Outcomes Study Short-Form 36 Questionnaire	12	No improvement
Waldorff (2012)	RCT	Counselling Psychosocial support	Depression Quality of life	Geriatric Depression Scale (GDS 30 item) European Quality of Life Visual Analogue Scale (EQVAS)	12	No significant difference

Waldorff (2012)	RCT	Counselling Psychosocial support	Depression Quality of life	Geriatric Depression Scale (GDS 30 item) European Quality of Life Visual Analogue Scale (EQVAS)	12	No significant difference
Tanner (2015)	RCT	<i>Individualised</i> care planning, linkage to dementia services, caregiver education and skill	Caregiver burden, depression, Quality of Life Number of unmet needs		18	No difference in outcomes

Table 3: Multicomponent

Interventions

Most trials we identified demonstrated favourable outcomes for carers, which can extend beyond the period of support delivered. For example, a post study analysis of the REACH trial (Holland,2009) demonstrated that those supported with a multifaceted intervention while their loved one was alive showed lower symptoms of complicated grief at long term follow up following bereavement.

Larger multicomponent trials have also allowed comparisons across ethnic groups. Belle et. al. (2006) compared outcomes of a combined education, psychological support and telephone based intervention across 3 groups in America (White/Caucasian, Black African American, and Latino). There were clear intergroup differences – Latinos showed significant benefit in all measured domains, and White/Caucasian gained greater social support. However no benefit was found in Black African American carers. While the explanation for this is not clear, this demonstrates the need for more culturally sensitive interventions, with further qualitative research needed.

Other

Other support interventions published includes befriending (Charlesworth, 2008) and poetry writing (Kidd et al, 2011).

Third sector organisations can provide befrienders which have a role for carers in signposting services, providing emotional support through companionship, conversation and being a 'listening ear'. These services have face validity in improving carers' wellbeing, health related quality of life, loneliness and perceived social support but a recent RCT (Charlesworth et al, 2008) failed to demonstrate benefit of services when compared to treatment as usual

Previous studies have shown the benefits of exercise include improved mental and physical health and better sleep. It seems reasonable to assume that these benefits could also be demonstrated in carers and a small number of studies have investigated this. In a small RCT (intervention group n=16), Stella (2011) showed that a 6 month exercise programme for both patients with dementia and their carers consisting of aerobic and balance exercises for 60 minutes 3 times per week decreased neuropsychiatric symptoms and depression in people with dementia and significantly reduced burden in caregivers. The authors attributed the reduction in burden in the carer to an improvement in neuropsychiatric symptoms in the patient with dementia. A major strength of the intervention was that it targeted both patient and carer simultaneously, although larger studies with greater power would be required to confirm the results. A similar study (Hirano, 2011) showed that moderate exercise 3 times per week could reduce caregiver burden and improve sleep, although again numbers in the intervention group (n=17) were small. In contrast, a larger RCT (n=157) by Connell (2009) did not demonstrate a significant benefit of exercise for carers in terms of reducing burden, depressive symptoms or perceived stress. At baseline however, those randomised to intervention spent significantly greater time exercising than controls which may have skewed results. Furthermore exercise goals were self-selected by participating individuals in the intervention group with considerable variability, which may account for no significant difference between those exercising and not. Charbonneau (2011) looked at adapting a leisure programme for patients with dementia, with a view to specifically maintaining leisure practice of daily life but failed to quantitatively demonstrate an improvement in caregiver well-being. While caregivers in the intervention group initially showed an improvement in self efficacy, this was not sustained.

Kidd (2011) reasoned that a simple poetry writing intervention may benefit caregivers by providing a means of expressing some of the challenges they face. Carers were given open ended instructions to write poetry over a 4 week period. Most chose to write about their caregiving situation and expressed an increased sense of acceptance with their caregiving role as a result. However, the results are not generalisable due to the small and homogenous sample.

Conclusions

- There is a rapidly expanding evidence base for psychosocial interventions to support carers of patients with dementia, but challenges of significant heterogeneity both in interventions studied and outcomes measured make drawing generalised conclusions difficult
- Support interventions are more likely to be effective if:
 - Multiple supports are offered (i.e. A 'multicomponent' approach is used)
 - Educational interventions provide opportunity for active learning (e.g. role play scenarios rather than 'information only')
 - They are simple – the more complicated an intervention is, the less likely a carer is to adhere to it
- Distance interventions can be effective, and should be considered especially for older carers, and those in isolated rural locations
- Simply allocating a specific key worker, providing written information only or referring on to peer support groups are not likely to be effective

Learning Objectives

1. Consider the risks of both physical and psychological harm experienced by carers of people with dementia, often referred to as carer burden.
2. Be aware of the interventions available for the support of carers of people with dementia:
3. Consider the evidence for the effectiveness of these interventions, and be aware of the limitations of the evidence.

MCQs

Regarding the evidence base for supports for Caregivers of people with dementia: Each question has only 1 correct answer.

- Drawing generalised conclusions regarding their effectiveness is easy F
- Longer, complex interventions are more effective than short, simple interventions F
- There is no evidence that distance based interventions are effective F
- Referring carers to Alzheimer's UK groups is the only thing you can do F
- A combination of different interventions at different times is most effective T

Education groups for carers:

- Should Provide support over several months F
- Should promote active learning T
- Culturally sensitive adaptations do not work F
- Is less effective for male carers F
- Has been shown to reduce rates of depression in carers F

Formal Approaches to care:

Includes care management, care programming and use of specialist nurses to deliver care	T
Formal care management has consistent evidence of effectiveness	F
Use of a pro forma to trigger appropriate care pathways for carers and can reduce anxiety	F
Caregiver held records can reduce carer anxiety	F
Regular Care meetings have been shown to reduce depression in carers	F
Use of telecare for carers of people with dementia	
Use of technology to support older carers does not work	F
Providing telephone support to carers can be effective in reducing caregiver stress	T
Telecare is not effective in providing support to male carers	F
There is strong evidence that computer based supports decrease perceived burden in carers	F
There is no evidence that skill training DVDs are helpful	F

Multicomponent interventions:

May include combinations of support, education, counselling, and psychology T

Trials are too small to generalise results F

Interventions are too complicated and expensive to work F

The evidence suggests the most effective combination includes
psychoeducation and CBT F

Does not reduce burden of caring in Latino caregivers F

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